

Orange County Substance Exposed Newborns (SEN) Study Data Workgroup Proposed Data Protocol

Background

Following the recommendations of the Oversight Committee during the March meeting, the Data Committee is further developing the Substance Exposed Newborns Study. The proposed study involves the utilization and exchange of existing SSA CWS/CMS and HCA CalOMs data, avoiding the level of effort associated with a formal study involving individualized data collection forms.

This approach leverages an existing CWS/CMS data extraction model created by SSA. This data model provides the ability to extract information on all caregivers noted on the child welfare case plan, and can compile case-level data based on whether the adult in the case plan had a substance abuse-related service objective and planned activity as a component of the case plan. This summary includes adults who may have open dependency cases. This analysis includes whether the adult was referred for: substance abuse testing; outpatient treatment; inpatient treatment; substance abuse services; participation in 12-Step Program; or participation in more than one type of program. The results of this data model led to an initial comparison between available 2007 CWS/CMS data on parents affected by substance abuse to 2007 CalOMs data available on parents receiving treatment through HCA.

	<i>2007 CWS/CMS Data</i>	<i>2007 CalOMs Data</i>
Parents	<ul style="list-style-type: none"> • 1,566 parents with at least one substance abuse program planned activity <ul style="list-style-type: none"> ○ 45% Fathers (710) ○ 55% Mothers (858) • Among the 1,566 parents with a substance abuse-related planned activity, planned services included: <ul style="list-style-type: none"> ○ 92% substance abuse testing (1,436) ○ 62% outpatient treatment (974) ○ 3% inpatient treatment (40) ○ 1% refer for substance abuse services (162) ○ 56% 12-Step Program (870) ○ 71% more than one program 	<ul style="list-style-type: none"> • 3,646 adults had at least one child when they entered a HCA substance abuse treatment program <ul style="list-style-type: none"> ○ 59% Fathers (2,169) ○ 40% Mothers (1,475) ○ 3% pregnant at admission (121) ○ 2% referred by DDC or CPS (81) ○ 20% have at least one child living with someone else because of child protection court order (713) ○ 8% have at least one child living with someone else and parental rights terminated (303) • 45 pregnant women with no other children • Among the 3,646 adults with at least one child <ul style="list-style-type: none"> ○ 71% received outpatient services (2,594) ○ 15% received residential treatment (556) ○ 17% received residential detox (496) ○ 3% CalWorks recipients (144) ○ 2% Tx under CalWorks welfare-to-work (71)
Children	<ul style="list-style-type: none"> • 2,237 children related to these 1,566 parents with active cases <ul style="list-style-type: none"> ○ 49% are under 6 years old (1102) 	<ul style="list-style-type: none"> • 7,100 children affected (approx) <ul style="list-style-type: none"> ○ 36% are under 6 years old (2,547) • 1,516 children living with someone else because of child protection court order <ul style="list-style-type: none"> ○ 38% children living with someone else and parental rights terminated (571)

This model can also extract parent information including names, dates of birth, and gender. This capability provides an opportunity to conduct relatively automated data exchange and matching between CWS/CMS and CalOMS parent data, and could result in better cross-system tracking of parent, child and family outcomes. Outcomes that can be tracked include parent treatment entry and completion, family reunification, time to reunification, and time to child permanency.

Building on these initial efforts, the Data Committee developed and presented the SEN Study concept to the Oversight Committee. The SEN Study concept agreed upon by the Oversight Committee is summarized in the following table.

Description	Expected Outcome	Staff/Resources
<p>SSA Research and Evaluation Unit will compile the list of SENs and will track outcomes through CWS/CMS.</p> <p>SSA Research and Evaluation Unit will determine how to incorporate the SEN data with the CWS/CMS data extraction model that was created with the planned services activity. Parent information may be able to be extracted from SEN case data into the data model based on a special project code.</p> <p>A limited SSA and HCA data exchange and matching is proposed. Using above model to generate a list of parents, HCA sends CalOMS data on these individuals to SSA Research and Evaluation Unit. The data recipient can upload the data in SPSS and conduct the analyses.</p> <p>This parent population may require a modified release of information consent form.</p>	<p>Coordination between SSA and HCA to exchange data on these SEN cases</p> <p>Provides a small sample for developing and testing of a data exchange, matching and analysis protocol</p> <p>Develop consistency in how and when special project codes are applied to SENs.</p> <p>Analyses of CWS/CMS and CalOMS data will yield child welfare and treatment outcomes, without requiring staff time to collect additional data.</p>	<p>SSA Research and Evaluation Unit's time for CWS/CMS data extraction, formatting, matching and analysis</p> <p>SSA IT staff time to query CWS/CMS and update the model by extracting for each SEN data on parents' planned service activities</p> <p>HCA staff time to extract CalOMs parent data</p> <p>May require both SSA Specialized Services and HCA intake staff time to ensure appropriate consent forms are signed</p>

One goal of this SEN study is to identify, detail and execute an aggregate data sharing protocol between SSA and HCA in this small subset of families. A further goal of this study is to understand and develop a client and family level protocol for sharing information that supports multidisciplinary case planning, facilitating engagement of families in treatment and child welfare services, then policies and systems must be further examined.

This proposal outlines the anticipated tasks, proposed staff to be assigned, and remaining questions in the data collection, data exchange and analyses. The intent of this protocol is to develop and implement a data and information exchange process that serves to better track mutual clients between SSA and HCA, specifically parents of SENs, and assess parent, child and family outcomes for program improvement purposes. This proposal is a draft for the purposes of reaction and comment.

Data Collection and Exchange Protocol

1. SSA Research (Robin O'Neil) receives a monthly list of SENs from the SSA Specialized Family Services Unit. She compiles the list of SEN cases and assigns them a project ID number. Each month there are approximately 6-10 SENs.

- These cases will involve SENs who are remaining at home or who have been removed. Parents may or may not be involved in Dependency Drug Court (DDC).
 - Siblings of these children will also be tracked if they are in an open Child Welfare case.
 - SSA Research will develop (e.g. specify Excel file rows and columns) and maintain the master data tracking file. This file will include: SENs, additional involved children, demographic information, child welfare placement and permanency outcomes, parent service objectives and planned activities provided by SSA IT (see below), and substance abuse treatment data by HCA (see below.)
2. SSA IT (Vic Shaverdian) will modify the existing data model to allow for an automated extraction of parent information from CWS/CMS, including substance abuse-related service objective, planned activity, names, gender, date of birth and, if available, alternative names and social security number (or last 4 digits).
 3. SSA Research (Robin) coordinates with SSA IT (Vic) on a monthly basis for CWS/CMS parent data extraction based on the list of SEN cases.
 4. Robin uploads the parent and child CWS/CMS data extraction results into an SPSS file.
 5. Robin sends the parent data to HCA QM (Curt Condon) on a quarterly basis.
 - It is anticipated that of the 6-10 SENs per month, there will be an associated 9-15 mothers and fathers identified each month (27-45 adults per quarter).
 - The list of adults will be sent each quarter as a cumulative list of parents identified. A query of the cumulative list of parents will need to occur on a quarterly basis to allow for the amount of time that may occur between referral to services, admission and discharge, as well as subsequent treatment episodes during the life of a child welfare case.
 6. HCA QM (Curt) matches the SSA parent data from CalOMs dataset provided by HCA BHS-IRIS (Robert Heidenrich) for extracting any possible admission and discharge record matches for that quarter.
 - This step involves further discussion to determine the parameters of the CalOMs database search (i.e. data elements requested) and format and organization of results (e.g. specify Excel file rows and columns).
 7. HCA QM (Curt) submits the results to SSA Research (Robin). The results will be submitted on a password protected electronic file.
 8. SSA Research (Robin) uploads the results into an SPSS file and matches this information to the master tracking file.
 9. This process is intended to be in operation for a 24-36 month period (7-11 quarters). SSA Research (Robin) will continue to upload CalOMs data and new CWS/CMS data on child placement and permanency outcomes for the cohort of SENs. (The size of the cohort and the question of maintaining ongoing analyses of outcomes for SENs is to be determined.)
 - SSA Research (Robin) will compile the list of SENs for a 12 month period. The intent is to follow the family outcomes over a 24 month period. SENs identified in month 12 will also be followed over a 24 month period, which means the data will be compiled and analyzed over a 36 month period.
 - Conduct a three-month PDSA to evaluate process and potential barriers.

Oversight Committee Review and Approval

The Data Committee requests direction on what measures are required by the agencies involved in the study to authorize data exchange, and requests the formal approval of the Oversight Committee of this data protocol in advance of any data exchange process being initiated. There are several options for Oversight Committee review and approval, including:

A. Research or Evaluation Protocol

This project may move forward as a research or program evaluation study. The Data Committee reviewed relevant sections of 42 CFR, HIPAA, 45 CFR 164.512(i), "Protecting Personal Health Information in Research: Understanding the HIPAA Privacy Rule" DHHS NIH Publication No. 03-5388¹ and the California Health & Safety Code § 11845.5(c).

For example the disclosure of identifying information without patient consent is allowable under 42 CFR, Subpart D, Section 2.52 for the purpose of conducting scientific research. In this example, the Oversight Committee members may authorize this data protocol. However, 42 CFR is only one component of the laws that address confidentiality. HCA and SSA are also subject to different requirements under HIPAA. A determination of the legal requirements may require an opinion that includes input from the HCA attorney.

The Data Committee will revise this protocol based on comments and recommendations of the Oversight Committee to resolve any concerns, questions or issues in advance of approval. This may be the most expedient method of initiating this proposed data study. If directed by the Oversight Committee, the Data Committee will seek IRB approval for this study as a 24-36 month research project.

B. Revised Release of Information Consent Forms

In this proposed data collection and exchange protocol, the use of parent names may require the Specialized Family Services (SFS) Unit to obtain a release of information from parents with SENs. Obtaining a signed release of information form that includes HCA will allow for both information and data sharing of parent information. SFS could utilize the existing DDC consent form, which is already in use for information sharing between SSA and HCA on DDC clients. While this may require an additional level of effort from the Specialized Services Worker to obtain these signed consent forms, signed consent forms would more likely provide the kind of assurances needed to share treatment data.

Beyond the scope of this SEN study, the release and exchange of information between SSA, HCA and the courts requires a further examination of the consent forms utilized by SSA and HCA. Helping systems to collaborate to improve outcomes at the family level is a primary goal of this project. Data-sharing at the family level offers the opportunity to examine what works and what does not work in terms of system responses. However, understanding and developing the policies and procedures that enable sharing information between agencies about individual cases for the purpose of multidisciplinary case planning, versus sharing data across systems in the aggregate, continues to pose a challenge in terms of preserving data integrity, client confidentiality, and parental rights to due process.

¹ available at http://privacyruleandresearch.nih.gov/pdf/HIPAA_Privacy_Rule_Booklet.pdf

One goal of this SEN study is to identify, detail and execute an aggregate data sharing protocol between SSA and HCA in this small subset of families. If a further goal of this study is to understand and develop a client and family level protocol for sharing information that supports multidisciplinary case planning, facilitating engagement of families in treatment and child welfare services, then policies and systems must be further examined.

There are several points in the case plan where information can be shared between HCA and SSA regarding these families. The NIATx process improvement discussion on May 20 can help identify these key points for information exchange. However, consistent and comprehensive release of information forms, perhaps utilizing the same format as used by clients in the DDC, can facilitate both information and data exchange.

While this may not be the most expedient means of getting this SEN study initiated, this could facilitate ongoing and sustainable data and information sharing. A subcommittee that includes counsel for HCA to develop a consent form might be something to consider as a viable long-term solution to confidentiality issues.

C. Memorandum of Understanding

This data protocol may serve as the content of a Memorandum of Understanding between SSA and HCA for a 24 month SEN data and information sharing study. An opinion including counsel for HCA will be needed to address this alternative.

D. Miscellaneous Court Order

Judge Kirkwood may issue a Miscellaneous Court Order that authorizes the sharing of information between SSA and HCA. This may be appropriate in any of the options listed above. Judge Hudson issued a similar Miscellaneous Court Order for a previous data sharing project. This previous order may need to be updated and reissued by Judge Kirkwood for this new effort.